CAREGIVER NAVIGATION GUIDE

Written Compendium & Glossary of Terms

2023

Created in partnership between WoodGreen Community Services,
East Toronto Health Partners (ETHP) and ETHP's Caregiver Advisory Group.

This guide is a compilation of texts based on the scripts developed for the video series: Caregiver Navigation Guide. The Caregiver Navigation Guide video series was developed in 2023 as a collaboration between WoodGreen Community Services, East Toronto Health Partners (ETHP) and ETHP's Caregiver Advisory Group.

Each text in this guide is based on a specific video and explores a different topic. The topics were identified by experienced caregivers to assist caregivers who are at the start of their caregiving journey to help them navigate the healthcare system. The videos frequently reference resources from other organizations and the links to these resources were added under the video descriptions (on WoodGreen's YouTube channel). The texts in this guide are transcriptions of the videos and include reference to the resources mentioned (hyperlinks to the resources are highlighted throughout the text).

This document is a quick-reference guide, which can also be printed and used in hard-copy, for ease of finding specific information covered in the videos. A glossary of terms commonly encountered by caregivers has also been added to define some technical words, terms and abbreviations that caregivers will come across when reading this guide or watching the videos.

A special thanks to the members of the ETHP Caregiver Advisory Group for their expertise and assistance throughout all aspects of this project and for their help in writing and reviewing the video scripts included in this guide. We would like to express our gratitude to the following caregivers: Aspa, Jill, Patty, Monica, Cindy, Pat, Uzma, Sarah, Sandra, Hannah and Khadija.

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Information for caregivers: How to navigate the healthcare system

If you're providing a family member, partner or friend with regular and ongoing care and help without being paid - you're a caregiver. The transition into the role of caregiver can be rocky and abrupt or it can happen slowly over time.

One of the best ways to prepare yourself for the various challenges you will be faced with when caregiving is to learn how to find, navigate and access various health and community resources. In this video we discuss how different healthcare providers can support you as a caregiver.

Normally, the first point of contact would be your care recipient's family doctor. They will provide a diagnosis and care plan, or a referral to a specialist.

You should inform them that you are the caregiver and provide them with your care recipient's written consent to grant you access to their health records, test results and other health information.

If you are new to caregiving, it is always a good idea to prepare a list of questions before a visit to the physician and ask for additional time during the visit to ask all your questions. During the appointment, it is also a good idea to bring a notebook and include a list of the patient's medications in addition to your list of questions.

Make sure to clarify any of the physician's instructions. Try to understand the overall course of the illness or recovery and what type of support and resources you may need at different stages.

When it comes to getting information on getting help at home, primary care providers may not be aware of the full range of supportive services that are available in the community. Also, some people in Ontario may not have access to a family doctor. That's why you should use these other supports:

Pharmacists can also be a great resource for caregivers. Pharmacists can be easier to access than medical professionals as they don't require an appointment. Pharmacists can provide guidance on understanding a diagnosis and the treatment process. They can also help when you have concerns with prescribed medications or any side effects.

It is also a good idea to join caregiver support groups, especially if you are a new caregiver. A caregiver support group can be an excellent resource for participants, offering information, resources and strategies specific to caring for someone. some caregiver support groups even focus on specific illnesses.

Joining a local caregiver support group can help you identify more accessible resources and support closer to home. They can provide a place to get help navigating the healthcare system, share feelings, make friends and learn from others who have walked a similar path.

Community organizations that have programs for seniors and caregivers, such as WoodGreen community services are another great resource. These organizations will connect you with a social worker who can provide information and access to different community supports.

Organizations like the Ontario Caregiver Organization are a tremendous resource for caregivers from all walks of life. To learn more, please visit their website, linked in the description box below.

Do not wait to learn more about your care recipient's condition and the services available to you. Often families do not reach out for help until there is a crisis. You can avoid that by reaching out as soon as you think you need help and support.

Resources for caregivers can be found on the Ontario Caregiver Organization website: https://ontariocaregiver.ca/for-caregivers/

I am a Caregiver Toolkit: https://ontariocaregiver.ca/wp-content/uploads/2021/06/OCO-starter-kit-for-Web-June9-2021.pdf

ELizz by SE Health Resource Library: https://carechannel.elizz.com/resources/ https://carechannel.elizz.com/

To help navigate these and similar caregiver resources, visit the ETHP service directory: https://services.ethp.ca/

Information for caregivers: How to find support if you are caregiving at a hospital or home

As a caregiver you will likely find yourself in a situation when you will have to navigate different healthcare settings such as: Hospitals, including the emergency department, Long Term Care homes, and home and community care. In any of these settings, you will interact with your Health Care Team. This team consists of the patient and the health care providers, such as surgeons, specialists, nurses, pharmacists, physiotherapists, and family doctors, to name a few.

As a caregiver, you are an integral part of your care recipient's healthcare team and your contact information should be in the patient's hospital record. Hospitals can be intimidating places with many policies and procedures that you may not be familiar with.

The best way to learn about what is going on is to get to know the nurses and let them know that you are the point of contact for the patient. Nurses are key sources of information for caregivers, can answer many of your questions and provide practical tips for caregiving. Also, meet with the attending doctor and explain that you want to be kept informed of important test results and included in medical decisions.

You should keep a running list of questions and find out when the doctor will be visiting patients so that you can be there to get your questions answered. Hospital social workers or

case managers can provide information on coordinating care and local caregiving resources. At the end of a hospital stay, they often help with creating a plan for when the person is discharged from the hospital.

There are several other staff roles that can also be a part of the healthcare team such as: dietitians, physio therapists, pathologists, radiologists, and other specialists. In some cases, the specialist may be a surgeon who has expertise in one area.

Home and Community Care Support Services case managers or care coordinators will determine your care recipient's eligibility for services depending on the level of follow-up care the patient needs.

Patients who can continue to live at home with some support are discharged to their home with home care. Receiving home care means that you and your care recipient will receive visits at home by Personal Support Workers. PSWs, as they are known, provide care and assistance to clients of all ages and their families and caregivers with tasks of daily living, such as personal care and hygiene and home management activities.

Caring for people suffering from Alzheimer's and Dementia at home can be especially challenging, and requires time and patience from family and other care providers. In many cases, people with Alzheimer's and Dementia cannot be left alone, requiring constant supervision, which can be difficult to provide long-term. Clinical Behavioural Response Specialists can provide assessment, treatment and care for older adults with cognitive impairment that can lead to challenging behaviours. Services are provided in the home, long term care, and acute care settings, as well as during transitions from one care setting to another.

Baycrest Caregiver Tools: https://www.baycrest.org/Baycrest/Health-Wellness/Baycrest-Quick-Response-Caregiver-Tool

UHN Patient Oriented Discharge Summary tool: https://pods-toolkit.uhnopenlab.ca/

Toronto Grace's Remote Care Monitoring program: https://www.torontograce.org/programs-services/remote-care-monitoring/

To help navigate these and similar caregiver resources, visit the ETHP service directory: https://services.ethp.ca/

Information for caregivers: How to find support if you are a caregiver of a frail or terminally ill person

When caring for a frail or terminally ill person, often there comes a point when it is no longer safe of feasible for them to remain in their own home.

A long-term care home, sometimes called a nursing home, is a place best suited for people who have difficulty managing their own care. They provide 24 - hour nursing and personal care where frail seniors can receive help with their daily activities. In addition to nurses, medical doctors and personal support workers, Long Term Care homes also employ recreation staff, physiotherapists and social workers.

All facilities are different, so it's important to get as much information as possible. If you see something that concerns you, talk to someone about it. Contact the director of care or administrator with your concerns or suggestions. Most Long-Term Care homes have a Family or Resident Council that you can join as well.

If your care recipient's journey is reaching the end-of-life stage, you may want the assistance of hospice or palliative care providers. Both hospice and palliative care are aimed at relieving suffering and improving quality of life.

Palliative care is specialized medical care that focuses on providing relief from the symptoms and stress of a serious illness. Palliative care may be given by: hospitals, home care agencies, cancer centres, and long-term care facilities. Your doctor or hospital can help you connect with palliative care specialists. Palliative care can start at the earlier stages of an illness and can be combined with other treatments aimed at reducing or curing illness, such as chemotherapy.

Hospice care is typically given to people with terminal conditions who are nearing the end of life. Often people are cared for at home and then come to a hospice for the final two or three weeks of their life. Hospice organizations also provide bereavement support programs to caregivers and families.

During the whole caregiver journey, it is important that you balance your caregiving duties with your own mental and physical well-being. Self-care can be a challenging concept for caregivers, as you may think it takes time away from your care recipient or other things you need to do. However, by practicing self-care, you can ensure you are well enough to support your care recipient.

There will be times when you might be struggling more than usual or are in a crisis, and you will need to seek out professional help. Professional support may include talking to your family doctor, a mental health therapist such as a psychiatrist, or contacting a crisis line. Some people may also see out their faith leaders as a source of support. Organizations like the Ontario Caregiver Organization are a tremendous resource for caregivers from all walks of life. They offer various programs and services for caregiver mental health and wellbeing.

Resources for caregivers can be found on the Ontario Caregiver Organization website: https://ontariocaregiver.ca/for-caregivers/

To help navigate these and similar caregiver resources, visit the ETHP service directory: https://services.ethp.ca/

Information for Caregivers: What to do when your care recipient is admitted at the Emergency Department or Hospital

When medical emergencies and other crises happen, the focus is on the care recipient and getting them the medical care they need. A visit to an Emergency Department often involves waiting a long time to be seen by a nurse or a doctor. It's probably going to be stressful.

Looking for documents and medication or trying to recall details of their medical history during an emotionally charged situation may be challenging. It is wise to have a plan, like having a pre-packed bag ready for your care recipient that you can 'grab-and-go' in case of emergency.

You should consider bringing the following items:

- A list of medications. Include the pharmacy's phone number (if you are using one pharmacy)
- Medical history notes (including any specialist doctors' names and phone numbers)
- A change of warm and comfy clothes, and slippers
- An old pair of glasses, and hearing aids
- A copy of the Power of Attorney
- A phone charger
- An eye mask and earplugs, lotion for dry skin, lip balm for dry and chapped lips and saline nose spray
- A book or magazine
- A water bottle and snacks

It is also a good idea to have a similar bag packed for yourself too and be prepared for what may be a long wait at the emergency room.

Identify yourself to the ER staff as the caregiver and let them know if you are the substitute decision maker or power of attorney so you can be kept informed and included in decisions.

Having the pre-packed bag is also useful in the event your care recipient is admitted to the hospital. If this happens, it is important that you again identify yourself as the caregiver to the hospital care team in order to be included as a member of the patient's care-planning team.

You need to familiarize yourself with the hospital's policy for visitors. The hospital provides care 24 hours a day, so know what the rules are about visiting and staying overnight. If needed, have the doctor write an order that allows you to be with the patient at all times.

As an advocate for your care recipient, it is important to remember that hospitals can also accommodate special considerations based on the unique care needs of the patient.

Every hospital has a patient relations department that can assist with these special considerations and facilitate your access to your care recipient so you can provide support. These departments are generally staffed 9 to 5, Monday to Friday. Outside of these hours, you could contact the clinical coordinator on call or speak to the nurses on duty.

When advocating for special considerations it is useful to know that hospital essential visits include visits for compassionate care, including critical illness, palliative care, hospice care, end of life, and Medical Assistance in Dying.

Also, they include visits relevant to the patient or client's physical care and mental well-being, including:

- Assistance with feeding, mobility and with personal care;
- Communication assistance for people with hearing, visual, speech, cognitive, intellectual or memory impairments, and those speaking a language other than English;
- Assistance by designated representatives for persons with disabilities, including provision of emotional support;
- Visits for supported decision making
- Visits for pediatric care, labour and delivery
- And Visits required to move belongings in or out of a patient's room

Whether at the Emergency Department or the hospital – you will be asked questions related to the care recipient's medical history. Medical histories and key dates can be difficult to remember and track. However, you should keep notes about the medical history such as specialists' appointments, diagnosis, medications prescribed, diagnostic tests results, hospitalizations, procedures, surgeries and have them readily available at the Emergency Department and hospital. Information about medical history is important for the healthcare team to know.

I am a Caregiver Toolkit: https://ontariocaregiver.ca/wp-content/uploads/2021/06/OCO-starter-kit-for-Web-June9-2021.pdf

To help navigate these and similar caregiver resources, visit the ETHP service directory: https://services.ethp.ca/

Information for caregivers: What to do if your care recipient is staying at the hospital

After being admitted at the hospital, patients have a lot to manage, but they're usually too sick or hurt to do it all. They need their caregiver to help. This video has information to help you prepare for a hospital stay.

An important first step at the hospital, is to get to know the nurses and let them know that you are the point of contact for the patient. Nurses are key sources of information and support and can answer many of your questions. Nurses can help you understand medical procedures and hospital processes. They can also provide practical tips for caregiving and tell you where to find more information. Also, if you are the substitute decision maker, or your care recipient has given consent, ask to meet with the attending doctor and explain that you want to be kept informed of important tests, diagnostic results and included in all medical decisions.

As a caregiver, your contact information should be in the patient's hospital record. If the substitute decision maker is different from the caregiver, it is important that the patient record includes contact information for both persons. For more information on substitute decision makers and power of attorney see our other video linked in the description box below. You will also want to ask for the best way to reach the doctor. You should keep a running list of questions and find out when the doctor will be visiting patients so that you can be there to get your questions answered. It also helps to write down the answers. If you don't understand what the doctor is saying, ask them to provide more explanation.

It's OK to speak up. One of the things you may want to ask is: If this was your mom or dad or child, what would you do? Inviting the doctor to step into your shoes is a helpful method to gauge how you may wish to proceed. As a patient advocate, it is helpful to familiarize yourself with the patient rights such as to be treated with dignity and respect and without discrimination, to receive information relating to any proposed treatment and options, and the right to second opinion. You may encounter situations when you will need to remind the health care team of the patient's rights.

New medications can be part of the treatment in hospital. Patients with chronic or serious diseases usually take many prescribed medications, as well as an array of non-prescription items. Ask the nursing staff to tell the patient and you, the name and purpose of medications given orally or through IV. Frequently, doctors at the hospital prescribe new medications and instruct the patient to stop taking previously prescribed drugs. Ask the doctor in hospital if you have questions or need clarification. Inform the family doctor or other specialists who have prescribed medication previously, of the change in prescribed medication. They may have concerns and questions for the hospital doctor.

Another important thing that needs to be discussed with the attending doctor is Medication reconciliation. This is the process of comparing a previous list of medications with an updated one. It should occur whenever there is a change in medications, care settings, or diagnosis. Medication reconciliation is particularly important when a patient is discharged and is moved from one level of care to another or discharged from the hospital.

As a caregiver you can help with this process by:
1. Keeping an up-to-date medication list.
2. Taking the list to all doctor's appointments, hospital stays, admission to a medical facility or nursing home.
3. Keeping the list updated any time a medication is added to or taken off the list.
4. Reminding the doctor or nurse about any known allergies or side-effects the patient has experienced in the past with certain medications. Medications that shouldn't be given should be highlighted or boldfaced.

You may ask for a copy of the list of medications upon discharge so you can give it to the family doctor. Sometimes the discharge notes may not reach your family doctor's office on-time.

Talk to the attending hospital doctor regarding the need of home care services so the doctor can put the request in the chart as part of the discharge plan. It's also helpful to meet with a hospital social worker or case manager. They can provide information on coordinating care and local caregiving resources. They often help with discharge planning issues, such as follow-up care. This is your opportunity to restate the need for home care services for your care recipient. Discharge plans are also sent to the family doctor so they can be kept informed about the hospital care and any needed follow ups.

To help navigate these and similar caregiver resources, visit the ETHP service directory: https://services.ethp.ca/

Information for caregivers: What to do when your care recipient is being discharged from the hospital

Leaving the hospital can be both exciting and stressful. Whether it was a long or short hospital stay, there is often some degree of apprehension about the discharge process. If there is ongoing care needed after a hospital inpatient stay, a discharge plan should be developed and shared before the care recipient leaves the hospital. The discharge plan is also sent to the family doctor, although it can take some time to reach them.

If there are any outpatient tests prescribed, advocate that your family member or friend stay at the hospital for most of those tests. Because, after they are discharged from the hospital, it can be difficult trying to book all the appointments yourself. It also may be a challenge taking the person for outpatient tests by yourself, especially if you are a caregiver of an elderly person or someone with mobility issues.

Discharge from the hospital may be to any of these places:

- Home, with or without home care
- Long term care home
- Rehabilitation facility
- Complex continuing care facility
- Palliative care

The patient's care team generally determines any post-discharge care needs. Making these arrangements is done in conjunction with the patient and the patient's caregiver who should already be included as part of the care team. It can take quite a bit of research to decide which option best fits your needs.

Sometimes after a hospital stay, patients may need additional time to recover before they can go back home. For example, patients may be referred for rehabilitation or "rehab" services, where they can receive therapy to try to regain abilities they may have lost, or to help maintain function. Rehabilitation services are provided in various settings, such as inpatient

rehabilitation hospitals, nursing homes, specialized rehab units within hospitals, and other specialized settings.

The caregiver needs to confirm that before a discharge happens, the healthcare team has arranged for care to be in place. When being discharged home, make sure you have access to necessary equipment, supplies and additional services such as home and community care.

Meet with the hospital or rehab staff to be clear on instructions for care at home. It is also important that you inform the medical team about what you can or cannot do for your care recipient and what training you may need. Find out what symptoms and behaviors are to be expected. On the day of discharge, you should be given a discharge summary or package. A useful resource to help you at a time of discharge from the hospital can be found at the Ontario Caregiver Organization's website, linked in the description box below.

A follow up appointment with the family doctor after a hospital stay is frequently recommended. Discharge plans are sent to the patient's family doctor; however, they may not receive the information before the follow up appointment. It's recommended to take the discharge plan, including the up-to-date medication list, with you to the appointment.

There are many challenges related to when patients need to go to a Long-Term Care home. This can happen suddenly and, as a caregiver, you may not have enough time and resources to handle the situation. That's why it is important to have close communication with the hospital attending physician to get an idea of when the care recipient may be discharged so you can plan ahead.

Home and Community Care Support Services Care Coordinators are the ones who do the assessments to see if a person qualifies for the type of care provided in a long-term care home. They are also the ones who manage the waiting lists for long term care. Normally, when a patient or their caregiver is considering applying to a Long-Term Care home, they can choose up to five homes to be waitlisted for. Nursing homes in Ontario (both private and not for profit) have long waiting lists so patients may not be able to move to their preferred Long-Term Care home right away.

Alternate level of care is used in hospitals to describe patients who occupy a hospital bed but do not require the intensity of services provided in that care setting. Staying in a hospital longer than is medically necessary and being designated as alternative level of care can have negative effects on the patient, through risk of hospital-acquired infections and functional decline.

Effective November 2022, the government passed, what may be a temporary amendment to a regulation under the Emergency Management and Civil Protection Act. The amendment allows doctors to transfer ALC patients out of hospitals experiencing surges. These transfers may be to a long-term care facility that's not the patient's first choice, potentially far away from family members and loved ones who play a critical role in their day-to-day care.

Ontario Caregiver Organization's discharge from hospital checklist: https://ontariocaregiver.ca/wp-content/uploads/2020/01/discharge-checklist_2019.pdf

UHN Patient Oriented Discharge Summary tool: https://pods-toolkit.uhnopenlab.ca/

To help navigate these and similar caregiver resources, visit the ETHP service directory: https://services.ethp.ca/

Information for Caregivers: Legal Considerations PART 1 – Advanced Care Planning

Becoming a caregiver for a family member or a close friend changes the lives of everyone involved. If the care recipient's ability to maintain their independence changes, they might not be able to continue to manage their personal affairs in a manner they are accustomed to. Before this happens, there are things to be considered and discussed, such as legal, financial and health care decisions. This can help avoid issues down the line. This process is called advanced care planning.

Advanced care planning gives a care recipient a chance to plan for when they might not able to make or communicate their health care choices. It's important for them to make their preferences know such as what medical treatment and care they would and wouldn't want if they became very ill. This helps ensure their wishes can be followed and gives guidance to caregivers. This could include the care recipient's preferences about receiving CPR, breathing through ventilator, tube feeding, receiving intravenous fluids, and receiving pain relief.

Discussions about "what-if" and "worst-case" scenarios can be uncomfortable for caregivers and the people in their care. It is helpful to position these situations in the future, and distinguish them from present-day events. It is understandable that care recipients may not wish to discuss "worst-case scenarios" and imagine themselves vulnerable and helpless. However, waiting until these situations happen can cause a lot of stress and make these conversations even more difficult, and sometimes impossible, to have. That's why having advance directives, which are written instructions about health care wishes, can be very helpful for caregivers. If your care recipient can no longer speak for themselves, these directives will inform their health care team about their wishes and health care choices.

A great resource on advanced care planning and the role of substitute decision makers can be found on the Advanced Care Planning Ontario website, linked in the description box below.

Advanced Care Planning Ontario information on advanced care planning and the role of substitute decision makers: https://advancecareplanningontario.ca/resources-educational-support/resource-guide

To help navigate these and similar caregiver resources, visit the ETHP service directory: https://services.ethp.ca/

Information for Caregivers: Legal Considerations PART 2 - Substitute Decision Maker and Power of Attorney

In this video, we are going to explore the terms Substitute Decision Maker and Power of Attorney and what they mean for caregivers.

What is a substitute decision maker? A substitute decision-maker is someone who makes decisions on another person's behalf if they become unable to make those decisions themselves. Doctors or other health care providers must contact a substitute decision-maker for their consent before they can give treatment to a care recipient who is unable to consent.

Its important to note that caregivers are not automatically Substitute Decision Makers. If the care recipient has not chosen and legally appointed a substitute decision maker, Ontario has legislation that automatically chooses who will make health care decisions on their behalf.

The Health Care Consent Act lays out who this would be. For most people, this is their closest living relative who is capable and at least 16 years old in the following order:

- Spouse or partner, then
- Parents or children, followed by
- Siblings, and lastly
- Other relatives

However, the care recipient can choose the person to make decisions on their behalf and legally appoint them as a Substitute Decision Maker. That's when a Power of Attorney for Personal Care is required.

A Power of Attorney for Personal Care is a legal document that gives someone the right to make healthcare and other personal care decisions on behalf of a care recipient. The person with the Power of Attorney will be able to make almost any decision of a personal nature such as medical treatment, housing, food, hygiene, clothing and safety. There is a free form that can be used, linked in the description box below. There is no need to hire a lawyer to create one. The document should include the name of one or more persons to act as the power attorney for personal care and needs to be signed and dated. It must also be signed by two witnesses. Ontario has rules about who can act as a witness. When creating a Power of Attorney, it can be helpful to keep it simple.

Most people have a Power of Attorney document that covers property, finances and Personal Care. This makes sense because some healthcare decisions, especially those that involve costly treatment or care plans, also have financial implications. A great resource on preparing a Power of Attorney can be found on the Ontario government website Linked in the description box below.

As a last resort, if a person does not have any surviving close relatives or a Power of Attorney, a Public Guardian and Trustee is appointed. This is rare, especially in cases of personal care

decisions. The Public Guardian and Trustee Act serves to protect vulnerable adults, including older adults who may be victims of financial and other types of elder abuse.

It's important to remember, a substitute decision maker is only called upon if the person in their care is unable to make their own health care decisions (like if they are in a coma or their illness has impaired their ability to make decisions). Also, any written documents such as power of attorneys for personal care only come into effect under these circumstances. To learn more about substitute decision making, visit the Sunnybrook Hospital website linked in the description box below.

Advanced Care Planning Ontario information on advanced care planning and the role of substitute decision makers: https://advancecareplanningontario.ca/resources-educational-support/resource-guide

Sunnybrook's The Role and Responsibilities of a SDM:
https://sunnybrook.ca/uploads/SDM_1306.pdf

To help navigate these and similar caregiver resources, visit the ETHP service directory:
https://services.ethp.ca/

Information for Caregivers: Legal Considerations PART 3 - Patient Rights

As a caregiver and someone who will advocate on behalf of a care recipient, it's important that you are aware of patient rights. These rights are protected by laws such as the Health Care Consent Act, the Long-Term Care Act and the Mental Health Act.

In general, patient rights include the right to:

- Receive safe, timely and proper care.
- Give or refuse consent to any proposed treatment, and for any reason.
- Have a medical professional clearly explain health problems and treatments.
- Participate in health care decisions.
- Ask questions and express concerns.
- Request a second opinion
- Be assured that personal information is confidential.
- Request to access your health information records.
- Request the transfer of your health records to another medical professional.
- Choose to discharge themselves at any time even against doctors' advice.

Patients have the right by law to access their own hospital health records either by viewing or requesting a copy. In a hospital or another health care facility, a copy of the health records can be obtained by submitting a written request to the Health Information Management department. This written request can be mailed or dropped off in person at the Health Information Management department, along with a copy of government issued photo

identification and a fee based on the number of pages. This fee is 30 dollars for up to 20 pages. For any additional pages, there is a charge of 25 cents per page, plus tax). The request may be submitted by the patient or their substitute decision maker.

When requested, copies of the health record may be released to health care providers outside the hospital to ensure the best continuing care. The attending physician at the hospital may also share reports or summaries of your treatment with other physicians and health care providers, so they are aware of any treatments or medications that may affect ongoing care.

Ontario government resource on preparing a Power of Attorney (page 27):
https://www.publications.gov.on.ca/store/20170501121/Free_Download_Files/300975.pdf

Sunnybrook Hospital information on roles and responsibilities of substitute decision makers:
https://sunnybrook.ca/uploads/1/patients/resources/roles-and-responsibilities-of-sdm-.pdf

To help navigate these and similar caregiver resources, visit the ETHP service directory:
https://services.ethp.ca/

Information for Caregivers: Legal Considerations PART 4 - Complaints

Caregivers often feel too intimidated to bring up concerns to a healthcare provider about the care provided to the care recipient. They could also fear retaliation if they're perceived as confrontational, demanding or complaining.

Do not be afraid to ask questions. Advocate for your person's care. If talking directly to the healthcare provider does not address an issue and if you feel that they have violated any of the patient rights, you can make a complaint. Patients or their caregivers make complaints so corrective actions will be taken to address an issue and to reduce the chance of that issue happening again.

Most hospitals have protocols for receiving and handling complaints. Contact the Patients relations department to learn about the process to file a complaint. Complaints can be made directly to a healthcare provider, the College of Physicians and Surgeons of Ontario, or to the Ontario Patient Ombudsman. Sometimes patients may feel a healthcare provider is too slow to respond or appears not to be taking the complaint seriously. In this case they may, for example, send a complaint to the College or the Patient Ombudsman, contact the news media, or voice their feelings on social media.

Caregivers need consent of the patient or the patient's substitute decision-maker to make a complaint and to share the patient's personal or health information in the complaint. The patient also needs to provide consent to The College, The Ombudsman or the care provider if they want their personal and health information shared with the caregiver for the purpose of attempting to resolve the complaint.

When it comes to Long-Term Care homes, many caregivers don't make complaints in fear of retaliation against their family member or friend residing in the home. Retaliation and fear of retaliation can be a reality for individuals living in Long Term care homes and their caregivers. If retaliation happens it could take many possible forms ranging from instances that are egregious or highly visible to more subtle actions. In some cases it can be difficult to know if the actions are the result of being short staffed, an emergency with another patient or several requests happening at the same time.

Some possible examples of retaliation include:

- Call bells not answered or answered slowly
- Food tray coming late past meal time
- Difficulty getting medications when needed
- Bathroom usage
- Not providing food and water when requested
- General lack of attentiveness
- Bullying

If you think the actions are deliberate and you are concerned that retaliation is happening, you should:

- Speak out about the retaliation you are seeing
- Talk to other families for support or attend the Family Council meetings and bring up issues there
- Identify supportive staff members in the building that you feel safe discussing concerns with
- Remember that staff fear consequences of complaints too, such as, getting fired, losing their license to practice, and lawsuits.
- When advocating for your care recipient be constructive and understanding
- Communicate that you want to be part of the solution

Caring for someone can be stressful, and collaboration between caregivers and health providers is in the best interest of the care recipient.

What are my rights as a patient? https://settlement.org/ontario/health/patients-rights-and-responsibilities/rights-and-responsibilities-of-patients/what-are-my-rights-as-a-patient/

HCCSS Patient Bill of Rights: https://healthcareathome.ca/patient-bill-of-rights/

To help navigate these and similar caregiver resources, visit the ETHP service directory: https://services.ethp.ca/

Information for Caregivers: PSW Care at Home PART 1 – Qualifying for Home and Community Care Support Services

Most people want to remain in their home with their family and familiar surroundings for as long as possible. One way to help make this possible is through accessing home support. Personal Support Workers (commonly referred to as PSWs) are trained care professionals who provide a range of supports to a care recipient. From bathing, dressing and toileting assistance, to accompaniment on outings or light housekeeping and meal preparation, PSWs are an integral part of our community and health care system.

There are different ways to access PSWs. Let's start with exploring Home and Community Care Support Services (HCCSS) - previously known as CCAC and then LHIN. They are responsible for assessing need, determining eligibility for people to receive government OHIP-funded support from, for example, PSWs, nurses, and occupational therapists – as well as access to long-term care homes in Ontario. We will take a closer look at long-term care homes and that application process in our "Right Place of Care" video.

HCCSS provides OHIP (government) funded PSWs that can assist a person with personal care tasks, such as bathing, toileting, dressing, feeding, and medication reminders. This is a free service covered by OHIP and is intended for persons with high needs. It is important to note that the care provided is limited and task oriented. The Home and Community Care Support Service's eligibility criteria for PSWs is based on a person's need for support with personal care tasks they are not able to do independently. This service does not assist with housekeeping.

The HCCSS is divided into geographic catchments, with Toronto Central catchment covering East York/ East Toronto Health Partners catchment area. For people located East of the map border, they reside in the Central East HCCSS catchment.

To be assessed for eligibility for OHIP-covered PSW support in East Toronto, call the Toronto Central Home and Community Care Support Services at 416 506-9888. When calling, the care recipient should be present so they can provide verbal consent for you to speak about their care to the HCCSS Representative, and you will need to have their OHIP card/# ready to provide to the Representative.

Please note: eligibility for PSW support is usually based on the need for personal care help – that means that to qualify, the care recipient likely with need to require help with toileting, dressing and/or bathing. If the person is independent in these areas, or unwilling to have a PSW help them, they will probably not qualify for HCCSS PSW hours.

The HCCSS phone Representative will do an initial eligibility screening and decide if a Care Coordinator should be assigned to do an in-home or phone assessment for the care recipient.

If the HCCSS Representative you speak to does NOT find the care recipient to be eligible, you can always call back and speak to someone else. Or if there is a change in the care needs of

your care recipient, you can call back and inquire about OHIP-covered PSW support at that time.

You can also talk to your family doctor, as they can make a direct referral for supports to Home and Community Care Support Services and also may be able advocate to your local HCCSS on your behalf.

Toronto Central Home and Community Care Support Services: 416 506-9888 To help navigate these and similar caregiver resources, visit the ETHP service directory: https://services.ethp.ca/

Information for Caregivers: PSW Care at Home PART 2 - Navigating Home & Community Care Support Services

For those eligible for an assessment for PSW services from Home & Community Care Support Services (HCCSS), the Care Coordinator will then be in touch to schedule a Home Visit (or in some cases, a telephone appointment) to complete a more thorough Care Assessment, known as a RAI. Depending on caseload and urgency, this could be several weeks later.

The Care Coordinator will speak with you (the caregiver) and the care recipient, to determine both your needs and discuss what HCCSS can provide. You can also request a PSW that speaks your preferred language, and they will try to accommodate if possible.

If you are able to provide clear and specific requests (these are the tasks/duties I would like the PSW to assist with," "these are the days/times that would work best for our schedule," etc) you can ask the Care Coordinator if they can accommodate these requests. If the Care Coordinator offers one 1-hour PSW visit weekly, but you know that your care recipient is used to having showers every other day, you can explain this to the Care Coordinator and ask if three 1-hour visits are possible. If the Care Coordinator offers one 1-hour PSW visit weekly, but you know that your care recipient is used to having showers every other day, you can explain this to the Care Coordinator and ask if three 1-hour visits are possible. You can mention if the care recipient had a recent fall, or has an unsteady gait or medication that may contribute to the risk of falls, which may help to advocate for your situation.

For context: Most folks, who qualify for HCCSS PSW hours and are considered low-medium acuity will get 1-6 PSW hours/week with each visit being a minimum of 1 hour, and typically a maximum of 2, depending on the duties assigned to the PSW. (This would be for a shower 1-3 times a week + any other acceptable duties agreed upon by you and the Care Coordinator.) Someone with medium-high needs might receive 7-14 hours/week, with daily visits once or twice per day. Usually at this acuity level, the care recipient is incontinent and requires help with all of their Activities of Daily Living (ADLs). Sometimes people qualify for 15-28 hours/week – they usually are people who do not have a caregiver to help them, or live alone, are likely

bedbound, and require help with everything from repositioning in bed, to toileting, to dressing, meals, etc. In this kind of situation, the care recipient would probably be waiting for a Long-Term Care bed, and have a "crisis designation" on the waitlist(s).

Once the care recipient qualifies for HCCSS PSW hours covered under OHIP, the hours are contracted out to a service provider organization. The service provider organization will likely schedule a home visit to conduct their own assessment with you and your care recipient. The organization will then have a Scheduling Coordinator arrange the PSW hours with you. They will let you know if there are any changes to the PSW schedule.

If you feel your care recipient needs an increase in the number of hours provided, you would need to contact the *HCCSS Care Coordinator* for this. If you have questions about the schedule or the individual PSW visiting, you would contact the *Scheduling Coordinator at the service provider organization*.

PLEASE NOTE: Currently, and for the past decade, there has been a shortage of PSWs across the province. This results in organizations not always having PSWs available at your preferred times or when you need them. If your PSW calls in sick or takes vacation, the organization may not have someone readily available to fill in those hours.

In addition to PSWs, HCCSS Care Coordinators can also arrange & provide time-limited physiotherapy, nurse home visits (primarily wound care), Speech-Language Therapist assessment, some nutritional counseling, Occupational Therapist assessments for home safety, falls risks, and application for Assistive Devices funding through ADP Ontario. We will explore how to access these services in our "Community Supports" video.

Toronto Central Home and Community Care Support Services: 416 506-9888

To help navigate these and similar caregiver resources, visit the ETHP service directory: https://services.ethp.ca/

Information for Caregivers: PSW Care at Home PART 3 - Paid Services

Personal Support Workers (commonly referred to as PSWs) are trained care professionals who provide a range of supports to a care recipient. In reality, many folks may need and benefit from additional hours beyond what they are eligible for through HCCSS. There are 3 options for accessing paid PSW services:

The first and most affordable option is often through your local non-profit Community Support Services agency. Similar to the HCCSS, non-profit seniors' agencies provide PSWs to assist a person with personal care tasks such as bathing, toileting, dressing, feeding, and medication reminders. Some can assist with housekeeping and meaningful activities; however, these services face a high demand, and they may not have any PSWs available.

WoodGreen covers the majority of East Toronto – and there are other smaller agencies in the area as well. Non-profit agencies, like WoodGreen, receive funding from the government and private donations to help subsidize the cost of care for their clients. The subsidy is built into the hourly rates provided and as of January 2023, they typically charge anywhere from $18-28/hour, depending on the agency.

For people who are considered low-income (typically on Old Age Security, or Ontario Disability Support Program) you can ask for a financial assessment to see if you are eligible for further reduction in the hourly cost for PSW services.

The second option is to enlist a private PSW agency. There are several agencies available that service the East Toronto area. In addition to bathing, toileting, dressing, feeding, and medication reminders, these agencies can assist with housekeeping, laundry, trips into the community, meaningful and recreational activities, and exercises. Private agencies charge higher fees than non-profit agencies and therefore have more flexibility in what they can offer.

As of January 2023, their rates are typically $30-45/hour, depending on the agency, the service being provided, and the hours agreed upon. Usually, there is a 3-hour minimum for service. While this can quickly become a sizeable cost, private agencies are typically able to accommodate more desirable service hours and have a faster turnaround time for service requests.

The third option is for PSWs (or undesignated "care providers") to be hired privately. This can be a more affordable option than using a for-profit PSW agency. You would negotiate the pay rate directly with the worker, and you would need to seek out, interview, and hire the person. And if they are sick or unable to work, you would also have to arrange alternate help for your care recipient. You can use a private brokering agency, browse "seeking employment" ads/postings on caregiver & nanny finding websites, or find someone through word of mouth (asking people you know for referrals).

If you choose to hire a caregiver independently, then you would be the employer rather than an agency. You could arrange for the tasks to be completed to be flexible and based on what the person needs, and what the PSW/care provider is comfortable and capable of doing. They may also be willing to discuss live-in caregiving – you would need to negotiate the fees for this with them. It is generally recommended you ask the PSW, or the private brokering agency, if they can provide a valid Vulnerable Sector Search (VSS). The Vulnerable Sector Search lets you know a person does not have a criminal background or any other infractions in their past. This helps to protect care recipients and their families. It's recommended that you ask the PSW you are hiring independently or the agency you are using, to provide a current VSS.

Beyond PSW care at home, your friends and family may also be able to help in looking after your care recipient. Perhaps there are situations where showering or toileting isn't needed, and the person simply needs someone to sit and socialize with them. This could be an ideal situation where another family member or friend could come over and provide you with an

opportunity to have time to yourself. This "break" in caregiving is often referred to as respite. In the next video, we will explore different services and programs available in your community, including other opportunities for respite.

To help navigate these and similar caregiver resources, visit the ETHP service directory: https://services.ethp.ca/

Information for Caregivers: Community Programs & Supports PART 1 - Home and Community Care Support Services Beyond Personal Support Workers (PSWs)

Whether you are helping your care recipient in healing or ongoing management of an illness, chronic condition or injury, there are home care supports available beyond the PSW supports that are provided by the government-funded Home and Community Care Support Services (HCCSS). For information on PSW supports see our videos on this topic.

In this video, we go over the types of supports, beyond PSWs, that are available to care recipients from Home and Community Support Services. Often these supports are set up when someone is discharged from the hospital, but they can also be put in place by the care recipient's family doctor or HCCSS Care Coordinator, as appropriate.

The first of these supports is home visits by nurses. These can be arranged for your care recipient if they are continuing to need medical assistance at home for things, for example, like wound care, medical injections and taking medications.

There are some tasks that can be delegated by the nurse to personal support workers or PSWs. A PSW must be fully trained to do the task. Training involves one to three teaching sessions in the care recipient's home with the appropriate professional demonstrating the procedure and then supervising the PSW while they perform the task. Only when all parties feel comfortable that the training is sufficient can the PSW perform the task without direct supervision. PSWs can only perform delegated tasks if the care recipient is in stable health and the act is routine for the care recipient, such as catheter care, applying compression stockings, or G-tube feeding.

HCCSS can provide physiotherapy; they offer a time-limited number of sessions that are usually done in-home once a week. In-home physiotherapy is typically provided to homebound care recipients to improve range of motion, strength and balance. Some people may be referred to out-patient physiotherapy instead.

Often the exercises prescribed by the physiotherapist are meant to be done daily. If your care recipient needs to be cued or guided to do daily exercises and is also receiving PSW home care from HCCSS, you can request that the PSWs are scheduled to attend the physiotherapy sessions with the care recipient. The PSW learns the exercises too, and as delegated by the physiotherapist, can then help the care recipient do their daily exercises.

Your care recipient may also be connected to a Speech-Language Pathologist through HCCSS that can assess swallowing and determine the type of food texture and what thickness of liquids is safest for your care recipient to consume.

For concerns around nourishment and sufficient food intake, a dietician service may be enlisted to provide you and your care recipient with nutritional counseling.

An occupational therapist (commonly referred to as an "OT") may conduct a "home safety assessment" of your care recipient's living space to determine if there are any physical risks for falls such as loose rugs, uneven flooring, and clutter. They can also assess the need for equipment such as a hospital bed, raised toilet seat or bath transfer chair and can help to order what is needed. If the care recipient has mobility issues, they also can assess and help identify an appropriate walker or wheelchair, and can assist with completing the funding application for funding from the Ontario Assistive Devices Program (ADP). We will discuss this grant and other funding opportunities in par three of community supports & programs.

Your care recipient's HCCSS care coordinator can also put them on the waitlist for short-term-stays at Long Term Care homes. Some long-term care homes offer short-stay beds for temporary care, convalescent, or respite (caregiver relief) care. This provides caregivers a break from their daily responsibilities to rest, rejuvenate, attend family functions or enjoy a vacation, secure in the knowledge that their loved one is safe and their health care needs are being met.

In this program, your care recipient can stay in a Long-Term Care Home for up to 60 days at one time and as many as 90 days each year. There is a daily fee ($62 as of January 2022) for short-term respite. Currently, there is no form of government financial assistance available for a respite bed. You will be required to pay by the day and some Long-Term Care Homes require full payment when checking-in your care recipient.

If your care recipient is eligible for a short-stay placement in a Long-Term Care Home, you may choose up to five homes. Bookings are on a first come, first served basis and should be reserved well in advance (up to 6 or even 9 months prior). If the dates you want are not available at your first choice of a Long-Term Care Home, the application will be sent to the next choice on your list. If you prefer, you can wait for your first choice Long-Term Care Home and take whatever dates become available.

Toronto Central Home and Community Care Support Services: 416 506-9888

To help navigate these and similar caregiver resources, visit the ETHP service directory: https://services.ethp.ca/

Information for Caregivers: Community Programs & Supports PART 2 - Not-for-profit, Community-based Organizations

As a caregiver, there can be times when you feel overwhelmed and isolated in trying to care for your loved one. However, there are programs and supports available to help lighten your load and connect you and your care recipient back to your community.

Caregiver relief, commonly referred to as "respite", can come in a variety of forms. Personal Support Worker (PSW) home care, shared care-taking responsibilities with friends and other family members, and community-based programming provided by not-for-profit organizations are all options for respite.

Tip: For low-income caregivers, it can be worthwhile to request a "subsidy assessment" for any or all of the services that have a fee. If eligible, you can receive services subsidized on a sliding scale in accordance with your financial situation.

Adult day programs (ADPs) provide supervised programing in a group setting to the frail elderly, people with disabilities or those living with dementia. The programs offered may include leisure or therapeutic activities, socialization, healthy meals and personal care. These programs can offer a change in environment for your care recipient. Research has found that day programs offer many benefits for people living with dementia, including:

1. Help people remain living at home longer,
2. Enhance mood,
3. Improve sleep,
4. And even help with cognitive function.

Some research and health care providers recommend that persons with dementia attend a day program at least twice a week to gain the benefits.

Day programs provide valuable care, and can also be helpful in lessening the costs of hiring individual PSW care. Day programs cost an average of $25.00 to $35.00 per day. In comparison, PSWs can cost $25.00 to $35.00 per hour. There are even a select few Adult Day Programs in Toronto that also offer 24-hour stays at their program, such as the Providence Healthcare ADP in East Toronto.

For caregivers and more independent care recipients, there are also **Senior Active Living Centres** that offer social, cultural, learning and recreational programs for seniors that promote health, well-being and social connections. Membership fees are nominal, usually around $30 a year. Membership may include access to: arts and culture programs, book clubs, fitness classes, lifelong learning classes and multicultural social groups, with special programs and events at an additional modest cost.

Getting around and to appointments can be a challenge for caregivers, especially when their care recipient has mobility issues. The TTC's **Wheel-Trans** provides specialized door-to-door, shared ride, accessible transit services for persons with physical disabilities using its fleet of

accessible minibuses or sometimes contracted accessible taxis. Users must apply and be assessed for eligibility. Fare is the same as a regular TTC trip, but, accompanying support persons who are registered and have a valid support person card, do not have to pay.

Please note that Wheel-Trans trips need to be booked in advance. Users are asked to book so that they plan to arrive 30 minutes prior to any appointments and there are often lengthy wait-times for the requested pick-up up times.

Toronto-RIDE provides assisted door-to-door transportation services in the Toronto-area to seniors 55 years of age and older and adults with disabilities who are not eligible for Wheel-Trans. Toronto Ride does have limited capacity, which means rides are only for those who have absolutely no other way of getting to their appointment. There are fees for the service. Trips can be booked up to 30 days in advance, and they can take clients to locations within the boundaries of the City of Toronto.

There are programs that help your care recipient to have healthy and nutritious meals. One of those programs is **Meals on Wheels**. Meals on Wheels enlists volunteers to deliver nutritious, affordable hot and frozen meals to seniors and adults living with disabilities. The volunteers can also provide at-home security and wellness checks when they do their deliveries. The meal costs are meant to be affordable – contact your local Meals on Wheels program for the costs. Accommodations can be made for people restricted to minced or pureed meals, as well as Halal requirements or cultural preferences such as Chinese hot meals.

Congregate dining programs offer affordable, nutritious hot meals usually at a senior centre or in another group social setting. Congregate meal programs provide older adults with positive social contacts with other seniors at the meal sites.

Friendly visiting programs are also a great way for care recipients to make more social connections. They provide regular volunteer visits or phone calls to older adults and people with disabilities who live alone. This one-on-one socialization and companionship help to reduce isolation and loneliness.

Medical escort programs provide seniors with door-to-door escorts to medical appointments, and sometimes include translation services.

The phrase “it takes a village” is a concept that can be applied to the health and safety of all community members, especially those most vulnerable and needing care. Remember, you aren’t alone and there are programs and community services available to support your caregiving journey.

WheelTrans: https://www.ttc.ca/wheel-trans/how-to-apply

TorontoRIDE: www.torontoride.ca

Meals on Wheels: https://www.mealsonwheels.ca/request-meals-on-wheels#RequestMeals

To help navigate these and similar caregiver resources, visit the ETHP service directory: https://services.ethp.ca/

Information for Caregivers: Community Programs & Supports PART 3 – Low Cost Services and Financial Supports

Caring for someone can be especially challenging when living on a low-income. Over a third of caregivers must use their personal finances and savings to pay for the needs of the person they care for. Often, they have to cut back on their or their family's spending to do so. Some will need a loan or sell off other assets to afford care. Those caring for children and older adults at the same time, known as the "sandwich generation caregivers" are facing the greatest financial hardships.

Unfortunately, benefits and tax credits for family caregivers are quite limited. The Ontario Caregiver Coalition has identified financial distress as a top advocacy priority, and as of January 2023, lobbying to the Ontario government to make Ontario's Caregiver Tax Credit Refundable and provide Ontario caregivers with access to Direct Funding is underway.

Their letter to the Ontario government, along with the Government of Canada's Benefits Finder tool can be found in the description box below.

There are some alternate financial supports caregivers may wish to pursue.

The **Assistive Devices Program (ADP Ontario)** helps people with long-term physical disabilities pay for customized equipment, like wheelchairs and hearing aids. The ADP also helps cover the cost of specialized supplies, such as those used with ostomies. They cover 75% of the cost for equipment and supplies. For these items, they are billed directly by the supplier and you pay 25% when you buy the item. In some cases, you receive a series of payments throughout the year to help cover the cost of supplies.
To qualify, you must:
- Be an Ontario resident
- Have a valid Ontario health card
- Have a disability requiring the equipment or supplies for six months or longer
They do not consider your income.
For more information visit the link in the description box below

The **Hardship Fund** is funding from the City of Toronto to help pay for certain medically based items/services such as incontinence products, eyeglasses, emergency dental work, medication, medical items (walkers, hearing aids, hospital beds, and more) or funeral expenses.
The eligibility criteria includes:
• Persons who live in Toronto (M- postal code)
• Persons who are low income, either from employment or a fixed income

(such as OAS or CPP).
• Persons who receive OW or ODSP are not eligible and should contact their case worker about how to apply for funding for medical supplies.

How to apply for the Hardship Fund:
• Collect your and your household's birth certificates, health cards, SIN cards, rental/lease agreement, bank statements for the last three months.
• Obtain an official quote estimate for the cost of the medical supplies from a supplier.
• For many items you will need documentation from a physician that confirms the necessity of the medical supplies. For example, if you are applying for funding for incontinence products, the physician can write a letter indicating that the person experiences incontinence and requires incontinence products (diapers, pads, wipes, etc.). This letter should also should also refer to the quote estimate of the products.
• Once these documents (in original) have been collected, you may phone the Hardship Fund to apply at 416-338-8888.
For more information visit the link in the description box below.

Homemakers and Nurses Services (HMNS) provides subsidized homemaking services through the City of Toronto. Considerably more affordable than paying privately, HMNS provides support with light housekeeping, laundry, shopping, and meal preparation. The Intake Caseworker at 416-392-8579 who will explain the program and requirements for eligibility.
For more information visit the link in the description box below.

Ceridian Cares is a charity that may offer financial grants up to a maximum of $5,000. This financial grant may be used towards clothing, footwear, food, basic household needs, medical needs or assistive devices.
You will be required to submit:
1. Recipient's Canadian birth certificate or permanent residence card,
2. Most recent year's Canada Revenue Agency (CRA) Notice of Assessment (include the Notice of Assessment for all income earners in the household),
3. Two quotes/estimates from vendor(s) or service provider(s) for the cost of the item(s) for which the financial assistance is being requested,
4. Letter from a third party (e.g. Doctor, Social Worker, Therapist).

Tips on completing the application:
- There is a section of the application referred to as "Request Type," where you will be asked to describe what you hope to use the financial grant for and how this grant will benefit your family. It is recommended you be very descriptive about the need your family is experiencing to elicit compassion, as you will want the reviewers to approve your application.
- You will be asked to submit quotes or estimates to demonstrate the need for financial assistance. This could include receipts of past prescriptions or medications-while indicating how often this will need to be paid for (for example: clearly write out how much is spent on this medication each year). This could also include attaching an "online shopping cart" from your

store of choice. It is important to include all items that the money could be used for (i.e. vitamins, food, meal supplements, incontinence products, clothing, cleaning supplies, assistive devices such as shower seat, etc.). This quote will help determine how much you receive as a grant.
For more information visit the link in the description box below.

March of Dimes Home or vehicle modifications to increase accessibility:
The program is available to permanent residents of Ontario who live with a substantial disability that impacts their mobility and daily function, and who can't afford the modifications they need to maximize their independence.
Anyone who qualifies can apply for:
- Up to $15,000 (lifetime maximum) for home modifications and/or;
- Up to $15,000 every ten years for vehicle modifications

To help you fill out the Application Assessment Form for the Home and Vehicle Modification Program (HVMP) there is an Applicant Assessment Guide, on the webpage link below, that will walk you through filling out the form. If you have any questions, this interactive guide may have the answers. For more information visit the link in the description box below.

Hilarity for Charity, also known as HFC® is working to award home care grants to those providing care to their loved ones living with Alzheimer's disease or other dementias. The goal of the home care grant is to provide exceptional home care to families affected by this disease, and to give these families support and rest. These grants are facilitated by Home Instead Senior Care, where available. These grants are for respite care hours, there is no cash value.

There are two grants, you may apply for one.
1. The Recharge Respite Grant is a one-time grant of 50 hours of respite care to be used within 3 months of being granted.
2. The Extended Relief Respite Grant is a six-month grant of 25 hours of respite care per week for six months (24 weeks)

To be eligible for the Recharge Relief Grant or the Extended Relief Respite Grant, the caregiver(s) or loved one living with Alzheimer's & dementia must fit within the following criteria:
• Currently living at home with Alzheimer's disease or related dementia.
• Caregiver(s) is facing financial and emotional hardships due to the unique challenges of Alzheimer's or related Dementia.
• Resides in the United States or Canada.

Tip for completing the application: It is recommended to be very descriptive about the need your family is experiencing to elicit compassion, as you will want the reviewers to approve your application. For more information visit the link in the description box below.

The **Alzheimer Society of Toronto** has run a **Caregiver Project** for grants to help support caregivers and their care recipients living in Toronto. To apply for the Caregiver Project, call AST intake at 416-322-6560 to book an appointment. For more information visit the link in the description box below.

Flash Funding - Crowd Sourced Donations can be an option for people comfortable setting up a **Go Fund Me** to raise money for a specific situation or cause.

For people in need that don't have the capacity or are uncomfortable with creating a Go Fund Me fundraising page, **Together Rising** supports women, families, and children in times of crisis by providing one-time grants of funds or goods. For more information visit the link in the description box below.

Similarly, **Resource Movement** operates an opt-in email list, the Rapid Response Support List, which connects list recipients with time-sensitive asks for support from social justice organizers and members of marginalized communities.

How to submit a request:
Email rapidresponse@resourcemovement.org to let them know you have a request for support.
They have found historically that answering these questions helps the success of your request:
Who would be receiving this support?
What is this support needed for?
What and how much support is needed (financial or otherwise)?
What is the deadline for receiving this support?
How can people contribute (email/password for e-transfers, donation link)?
For more information visit the link in the description box below.

PLEASE NOTE: The grants and financial supports outlined in this video can be challenging to come by, often with eligibility requirements, lengthy waitlists, and application forms that need to be completed. It can feel overwhelming to try to pursue these resources, and enlisting the help of a social worker, care navigator, or case manager can be useful in completing applications.

Your social worker may also be able to connect you with other financial supports, or know of grants as they become available. For example, though the Covid-19 pandemic, Flemingdon Health Centre's East Effort has provided grocery gift cards to families in need.

It can be worthwhile to request a "subsidy assessment" for any services or programs that do have a fee. If eligible, you could receive a subsidy on a sliding scale in accordance with your financial situation.

Beyond help with financial support, social workers with programs like **WoodGreen's Caregiver Support & Wellness program** offer free 1:1 counselling and facilitate caregiver support groups. If you feel anxious or inundated by your caregiving responsibilities, you're not alone. We all face

challenges on our caregiving journey. It's normal. Connecting to a social worker or support group can help.

Ontario Caregiver Coalition letter to the Ontario government: https://www.ontariocaregivercoalition.ca/_files/ugd/3e14ad_da03e05883c44a8591ec2e14f370bbb9.pdf

Government of Canada's Benefits Finder tool: https://benefitsfinder.services.gc.ca/hm

ADP Ontario: https://www.ontario.ca/page/assistive-devices-program#section-2

The Hardship Fund: www.toronto.ca/community-people/employment-social-support/health-support/?accordion=help-with-health-related-expenses-for-low-income-residents
Information about supplies or products covered: www.toronto.ca/community-people/employment-social-support/health-support/medical-supplies-and-devices/

HMNS: 416-392-8579 https://www.toronto.ca/community-people/children-parenting/seniors-services/seniors-health-services/homemakers-and-nurses-services/

Ceridian Cares: http://www.ceridiancares.ca/evaluation
Apply here: www.ceridiancares.ca/application

March of Dimes:
https://www.marchofdimes.ca/EN/programs/hvmp/Pages/HowtoApply.aspx

Hilarity for Charity: https://www.helpforalzheimersfamilies.com/get-help/hilarity-for-charity/
Apply here: https://helpforalzheimersfamilies.submittable.com/submit/2ec90a7e-c709-4406-8dda-3a354577e98d/hfc-in-home-care-grant-application

AST's Caregiver Project: https://alz.to/dementia-programs-activities/caregiver-project/

Together Rising: www.togetherrising.org/request-help-individual-or-family-application/

Resource Movement: rapidresponse@resourcemovement.org
https://docs.google.com/document/d/101PFl-QGWd8W33PlNmCMpB6C7zEh4z7ohmKanirbB08/edit

Flemingdon Health Centre's East Effort: https://www.fhc-chc.com/east-effort-community-covid-response-project/

To help navigate these and similar caregiver resources, visit the ETHP service directory: https://services.ethp.ca/

Information for Caregivers: Housing and Right Place of Care Options PART 1 -Rehabilitation hospitals and non-acute care inpatient programs for recovery, transition and reintegration

"Right place of care" is a term often used in hospitals and healthcare. But what does it mean? Essentially, it is patients being cared for in the most appropriate location by medically competent teams at the lowest possible cost. In these next videos, we are going to review the different locations people can receive care that best suits their needs.

This first video will review non-urgent care hospital settings and non-hospital transitional settings that include:

- Transitional Care units & Alternate Level of Care units in hospital and outside the hospital
- Rehab units in acute care hospitals and separate rehab hospitals

A person who is recovering in an acute care hospital from an injury or an illness may reach a point where they no longer require acute care, but instead need rehabilitation. Rehab can help people to regain strength and function. People who need rehab may be transferred to a Rehabilitation Hospital or may receive outpatient care in a community or hospital clinic. Some acute care hospitals have rehab units, however, typically these are separate, rehab-specific hospitals. The acute care hospital will determine if a person is eligible and would benefit from an inpatient rehabilitative program. As a caregiver you can ask the doctor or other hospital staff about this possibility.

It is important to note that some physical rehabilitation programs will not accept care recipients with cognitive impairment that impedes their therapy. For example - if the care recipient is unable to retain therapeutic instructions or understand direction, it is unlikely they will be considered a candidate for inpatient rehab.

In hospital, when someone has recovered to the point they are considered "medically stable" and no longer require hospital level care, but cannot be discharged, they may be designated as alternative level of care (ALC). This means they would be best cared for in a less intensive setting. The reasons people cannot be discharged are usually that they don't have the supports required to return home or they need more care than can be provided at home and don't yet have a place to go. As the names suggest, these beds are not a permanent residence and are for people who are waiting for their "right place of care" to become available.

A person may not be able to return home for a variety of reasons including, waiting for equipment to arrive, for a home to be adapted for accessibility, waiting for in-home care to be available, or waiting for you to recover from an injury or illness. As a caregiver, you may also have health issues, that in the moment, prevent you from providing the care you have been typically giving. It is also common that people designated ALC may not be able to return home at all and are waiting for a spot in a setting where they can receive ongoing care, such as a retirement home, assisted living, or long-term care setting.

If a person is designated as ALC or at risk of becoming ALC, they may be eligible for a stay in special units that provide inpatient care outside of hospitals. These include:

- Reactivation Care Centres
- Transitional Care Units
- Reintegration Care Units

These types of units or beds are not permanent and are for people who will either return home or be moving to a setting such as a retirement home, assisted living, or long-term care setting. There are similarities between these units – all offer varieties of inpatient non-acute care and are designed for people who are medically stable, and who need support to regain or maintain functioning, until they can transition to a setting for more care or a longer-term living situation.

Some hospitals have Reactivation Care Centres that they operate outside their main hospital. Patients in these units receive care from hospital staff. These are units for people who no longer need the intensity of an acute hospital care, but need support to continue to heal and recuperate. The focus in these settings the emphasis is on restorative care. Reactivation Care Centres can provide a place for further recovery and may offer therapies, rehabilitation and activation supports.

Other hospitals may offer similar options called Transitional Care Units. Michael Garron Hospital, for example, operates the offsite Kew Beach Unit, a comprehensive transitional care unit, for hospital patients who are ALC. Transitional care units typically offer around the clock nursing, personal care and other rehabilitation supports to support healing and maintain or regain functions. There are also Reintegration Care Units in Toronto that provides ALC patients or those at risk of becoming ALC, with a short-term supportive place to go post a hospital discharge. These units focus on reactivation and engagement and allow people time to plan and or prepare for a transition to home or a supportive environment, such as supportive housing or long-term care.

ALC beds can be hard to come by, and often the patient's healthcare team needs to advocate for a spot on their behalf. A bed may suddenly become available, but quite a distance from the hospital or the caregiver's residence. As of September 2022, Bill 7 - known as the "More Beds, Better Care Act," allows hospitals to transfer patients to nursing homes not of their choosing, given they are cleared for discharge and consent to the move out of hospital.

As a caregiver you may experience pressure to provide more care than you are able to realistically give. You may need to advocate for the care setting that you feel best supports you and your care recipient. If you think your care recipient would benefit from one of these types of setting, speak to the hospital staff about the options that may be available.

No matter which is best suited for your care recipient's next move, there is much to consider and having you as their care giver and advocate is an invaluable asset to them getting to their "right place of care".

To help navigate these and similar caregiver resources, visit the ETHP service directory: https://services.ethp.ca/

Information for Caregivers: Housing and Right Place of Care Options PART 2 - Non-profit and Rent-Geared-to-Income

Rent-geared-to-income or subsidized rental housing may be an option for people with limited or low income. This type of housing is limited and waiting lists tend to be long, so it may be difficult to access, but for those successful in applying, provides affordable housing for elders.

Toronto Seniors Housing Corporation provides subsidized rental housing for approximately 15,000 low- and moderate-income seniors in 83 buildings across the city. Rent-geared-to-income is sometimes referred to as subsidized rent or housing.

· Rent-geared-to-income is calculated at about 30% of your gross income.

· There is a waiting list for this type of housing. The waiting list is managed by the City of Toronto.

· MyAccesstoHousingTO is the online application portal for households applying for or managing their existing application for Rent-Geared-to-Income housing.

We are including a link in the description box below for Subsidized Housing Listings and how to apply. For people seeking rent-geared-to-income that are not seniors, the application process is the same for Toronto Community Housing Corp.

PLEASE NOTE: If you own a residential property, you must disclose this when you apply. You must sell the property, or your share in it, within six months of moving into subsidized housing. If you fail to do so, you may not receive an offer of housing, or lose your subsidy.

If you plan to live with your senior care-recipient, an additional form must be completed. We are including this in the description box below as well.

Some of the Toronto Seniors Housing Corporation buildings have Supportive Housing services in them provided by local community agencies. Supportive Housing promotes independent living for eligible residents by offering supports in their own homes that can include:

- assistance with personal care
- light housekeeping and laundry
- medication reminders
- safety checks
- light meal preparation
- wellness and health promotion activities and education
- referrals to community resources and assistance navigating the health care system

These supports are provided by personal support workers, PSWs. The care is free to eligible seniors. You will have to inquire with each building to determine whether they have this available to their residents.

Some community agencies (such as WoodGreen Community Services) also have their own Supportive Housing or assisted living buildings. For this housing, you need to apply directly through the agency for tenancy. We are including WoodGreen's Housing application in the description below.

Even with all the community programs and services available, sometimes having someone continue to live in their home is no longer possible. There can come a point when their care needs surpass what is available, and their "right place of care" changes.

In the next video, we are going to look at the options for places care recipients can live, and what each option entails. Often it can be confusing for people to differentiate between Long Term Care homes and Retirement Homes. However, the admission process, the cost, and the services provided by each are very different.

Toronto Community Housing: https://www.torontoseniorshousing.ca/become-a-tenant/our-buildings/
City of Toronto Subsidized Housing Listings: https://www.toronto.ca/community-people/employment-social-support/housing-support/rent-geared-to-income-subsidy/subsidized-housing-listings/#location=&lat=&lng=
TCH Overnight Caregiver Verification: https://www.toronto.ca/wp-content/uploads/2018/09/90d1-request-overnight-caregiver-verification-not-affiliated-with-an-agency.pdf
TSHC Supportive Housing: https://www.toronto.ca/community-people/employment-social-support/housing-support/subsidized-housing-housing-benefits/housing-providers/

WoodGreen housing application: https://woodgreen.wpenginepowered.com/wp-content/uploads/2021/11/WoodGreen_Housing_Application.pdf
All WoodGreen housing applications must include proof of status in Canada (i.e. birth certification, Canadian passport, Permanent Resident card, Refugee claimant form) and most recent Notice of Assessment.

To help navigate these and similar caregiver resources, visit the ETHP service directory: https://services.ethp.ca/

Information for Caregivers: Housing and Right Place of Care Options PART 3 - Moving to a supportive living environment

In this video we are going to discuss some options for care recipients who can no longer live at home. They may want or need a living situation with greater built-in supports and safety to meet their care needs, but aren't ready for long-term care, or are on a waitlist for long-term care. For these care recipients, moving to a supportive living environment, also known as a retirement home may be their "right place of care".

Let's start with retirement homes and the differences between this option and long-term care homes.

Long-term care homes are under the legislation of the Ontario Ministry of Health and Long Term Care whereas the Retirement Homes Regulatory Authority oversees Retirement Homes. Long-term care homes provide 24-hour nursing care and supervision to residents, are subsidized by the government and require an assessment from Home and Community Care Support Services to determine eligibility.

Retirement homes are designed for people who are more independent and costs are not subsidized by the government; people living in these homes pay the full cost of any care received as well as the rental of their private living space. People are able to apply directly to as many retirement homes as they wish and acceptance is up to each individual home. Retirement homes may offer different levels of care, and costs increase with the increase in care provision.

The first level of care offered by retirement homes is Independent living that is designed for high functioning older adults who are able to direct and provide most of their own care. It offers people an opportunity to downsize their living space, reduce responsibility for the care of a home and have access to social groups and planned activities. Prepared meals or dining room service are offered, along with laundry and or housekeeping.
- The approximate average monthly fees start at $3,000 per month.

The second level of care offered by retirement homes is assisted living for people who need more care and support in addition to meals, housekeeping and laundry. It involves personal support workers, PSWs, to assist with grooming, dressing, bathing, toileting, medication monitoring and transfers.

PSWs can be arranged through the retirement home OR Home and Community Care Support Services. Some people who are eligible choose to have Home and Community Care Support Services PSWs come to help with all or some of the needed personal care in the retirement home so that the care recipient does not have to pay additional fees to the retirement home.
- The approximate average monthly fees start at $4,000 per month.

Some retirement homes offer Memory Care floors. These settings are designed to ensure the safety of persons living with mild to moderate dementia. This can include locked doors with key passes, more supervision, and more support.

Many retirement homes will strive to provide support for persons with dementia until the end of life, however, keep in mind that people with dementia may experience increased medical needs and/or behavioural symptoms such as shouting or physical aggression, which are not always appropriate for retirement homes and therefore long-term care or another setting may need to be considered. - The approximate average monthly fees start at $6,000 per month.

The Retirement Homes Regulatory Authority has a website that provides a search tool to help locate retirement homes and residences. We have included the weblink in the description box

below, as well as a list of questions and tips to help you when choosing a retirement home or assisted living for your care recipient.

PLEASE NOTE: Retirement Home living may not be financially accessible to everyone. The fees outlined above are the starting point for costs of care, but location, services rendered, and the size of the unit can all add up. Most retirement homes are offered by for-profit companies, however, there are some not-for-profit providers.

Assisted living services are also provided by some not-for-profit community agencies in Toronto. As discussed in part two of "Housing options and right place of care", some community agencies offer assisted living supports to residents in select Toronto Seniors Housing buildings. Community agencies, such as WoodGreen Community Services, also offer dedicated and specialized residential housing programs for frail or high needs seniors. For these supports, you need to apply directly through the agency for tenancy. We are including WoodGreen's Housing application in the description below. To learn more about these assisted living options contact the Toronto Seniors Helpline at 416-217-2077.

Retirement Homes Regulatory Authority: https://www.rhra.ca/en/retirement-home-database/
RHRA Questions to ask: https://www.rhra.ca/wp-content/uploads/RHRA-Questions-to-Ask.pdf

WoodGreen housing application: https://woodgreen.wpenginepowered.com/wp-content/uploads/2021/11/WoodGreen_Housing_Application.pdf
All WoodGreen housing applications must include proof of status in Canada (i.e. birth certification, Canadian passport, Permanent Resident card, Refugee claimant form) and most recent Notice of Assessment.

Toronto Seniors Helpline: 416-217-2077

To help navigate these and similar caregiver resources, visit the ETHP service directory: https://services.ethp.ca/

Information for caregivers: Housing and Right Place of Care Options - PART 4: Moving to a Long-term Care Home

Even with all the community programs and services available, sometimes having someone continue to live in their home is no longer possible. If someone is living in supportive housing or a retirement home, there can come a point when their care needs surpass the support available there, and their "right place of care" changes. In this video we will focus on Long Term Care.

It can be confusing trying to distinguish between Long Term Care homes and Retirement Homes. They can be owned by the same company, and even situated on the same property, but the admission process, the cost, and the services provided by each are very different.

Long-term care homes provide 24-hour nursing, personal care and supervision to residents and are subsidized and regulated by the government. Long-term care homes are for persons who have high needs and require frequent access to supervision, nursing, or personal care support. Persons living in long-term care have access to services such as laundry, housekeeping, and congregate dining, where kitchen staff prepare all meals which are then served to residents in a large dining room.

There are different types of ownership structures for Long-term Care homes – they can operate either on a not-for-profit (municipal, charitable, non-profit nursing home) or for-profit basis. The majority of nursing homes in Ontario are operated as for-profit enterprises by corporate owners.

In the description box of this video, we have included a link to the Alzheimer Society's series on long-term care that includes topics such as considering long-term care, having a discussion about long-term care, and adjustments after the move to long-term care. We have also included a link in the description box below from the Ministry of Health and Long-Term Care. The ministry publishes an inspection report of each of the long term care homes in Ontario. You can review the report to help determine which homes you and your family are most comfortable with. This website also provides a list of long-term care homes broken down by city or LHIN so you could use this a centralized master list to explore homes in your desired location.

When it comes to the cost of Long-Term Care, the government pays the cost of providing nursing, personal care and food, as well as programs and support services while the resident pays for "accommodation" only. As of January 2023, the accommodation fee paid for by the resident is as follows:

Basic accommodation rates are approximately $1900 per month. (This is subject to a rate reduction if the resident is unable to pay this amount). Basic or 'standard' beds entail up to four residents per room. Most homes have fewer, and select few actually provide residents with their own room at the basic rate. These select few homes tend to have longer waitlists, given the 'value' placed on residents having their own rooms at the Basic fee rate.

Semi-private accommodation rates are approximately $2300. Semi-private beds entail either one roommate (two residents per room), or an individual bedroom with a shared washroom.

Private room accommodation rates are approximately $2800. Private beds entail the resident having their own bedroom and bathroom.

Please note: Accommodation rates change every July 1st.
People on low income, who have lived in Canada for 10+ years, and are planning to live in a basic bed accommodation may apply for a "rate reduction" based on their income.
Semi-private and private accommodations are NOT eligible for rate reductions.
For more information on how to apply, we have included a link in the description box below.

Applications for long-term care are made through Home and Community Care Support Services (HCCSS) and they are responsible for determining waitlist eligibility and placement coordination. To apply for long-term care, contact your local Home and Community Care Support Services office, or if your care recipient is already receiving services from them, contact their Care Coordinator. The HCCSS Care Coordinator assigned will complete an assessment, known as a RAI, to determine eligibility and whether a person's care needs can be met in a long-term care home.

The care recipient must provide informed and voluntary consent to the long-term care application being made. The Care Coordinator will want to know that the person applying is able to understand the information that's relevant to deciding about long-term care and able to understand the consequences of moving, or not moving, into long-term care.

If you wish to apply on behalf of your care recipient, the care recipient must provide consent. If they do not consent, the Care Coordinator will assess if your care recipient is deemed sound of mind to make this decision. An evaluation may be required if there is any question or uncertainty about the applicant's capacity to make informed decisions and the need for a substitute decision maker. If they are considered of sound mind, the long-term care application will not move forward.

Once eligibility is determined and consent obtained, the next step in the process is choosing up to five long-term care homes. Finding the right home for your care recipient can be a time-consuming endeavor.

If you are looking for a home that has specific cultural focus, dietary needs, or religious accommodations, you can ask the HCCSS Care Coordinator for help in identifying homes that meet these requirements. The Care Coordinator can also help in the selection by providing general information about homes in your area. It's also valuable to review online information about homes when trying to sort out which ones are suitable. In the description box below, we have also included links to resources to help with the Long-Term Care process.

After you have an idea of homes that might be right for your care recipient, it's helpful to arrange to take a tour of each to see if the home will suit your care recipient's needs.

The Ontario Government provides information about long-term care and the application process at the website below. This site also allows you to search to see what long-term care homes there are in a specific geography or to search for a home by name. The site provides information about each home, including the length of their waiting list, and links to the inspection reports the Ministry of Health and Long-Term Care publishes for each home.

Once a person has determined their choices for long-term care homes, they will inform their Care Coordinator of their choices in writing, through filling out the long-term care choice form. The Care Coordinator will send the application form to the chosen long-term care homes for review.

The selected long-term care homes will review the person's application to determine if they will accept and place the person on their waiting list. They will provide a letter indicating whether the person is approved for the waitlist for that home.

Some homes have very long waitlists (some are years long) and therefore it's a good idea to begin the process of applying to long-term care early.

It is important to note that there is also the possibility of "crisis admission" to long-term care, which is used as a last resort when it is significantly unsafe for a person to wait on the regular long-term care wait list. The Care Coordinator will assess and determine if a person is eligible for crisis admission.

Alzheimer Society's information series on long-term care: https://alzheimer.ca/en/help-support/im-caring-person-living-dementia/long-term-care

Toronto Central Home and Community Care Support Services: 416 506-9888
Long Term Care in Ontario: https://www.ontario.ca/page/long-term-care-ontario
LTC rate reduction: https://www.ontario.ca/page/get-help-paying-long-term-care
Map of nearby LTC homes:
https://www.ontario.ca/locations/longtermcare/search/?n=Toronto%2C+ON+M4J+1L2&lat=43.6793224&lng=-79.34180309999999&v=

Checklist to help caregivers assess their stress levels and help in your decision making around choosing long-term care as an option:
https://alzheimer.ca/sites/default/files/documents/Caregiver-stress-assessment-checklist--Alzheimer-Society.pdf
Things to consider when touring long-term care:
https://alzheimer.ca/sites/default/files/files/national/long-term-care/ltc_1_considerig_a_move_e.pdf
List of considerations when selecting a long-term care home:
http://healthcareathome.ca/torontocentral/en/Getting-Care/Getting-Long-Term-Care/Selecting-a-Home
Check-list to help you decide on what's important to you when considering a long-term care home: https://alzheimer.ca/sites/default/files/documents/Long-term-care-home-checklist-Alzheimer-Society_0.pdf
Resource handout to help families navigate moving to long-term care:
https://alzheimer.ca/sites/default/files/documents/Resources-for-long-term-care-Alzheimer-Society.pdf

To help navigate these and similar caregiver resources, visit the ETHP service directory:
https://services.ethp.ca/

Glossary of Acronyms, Terms, and Definitions

ADLs (Activities of daily living) - Actions a person must do by themselves to engage independently in everyday life, such as bathing, dressing, eating, being mobile, moving from bed to a chair and using the toilet.

Acute care - Medical care given for a short time to treat a specific illness or condition. This can include doctor visits, short hospital stays or surgery.

ADP (Adult day program) - Centers that provide companionship and help to older adults who need supervision during the day. The programs can help give a break to a round-the-clock caregiver.

ADP Ontario - Assistive Devices Program Ontario

Advance Care Planning - Advance care planning is the process of learning, considering, and sharing your preferences for future medical care in case you are unable to make your own decisions.

Advocate - An individual or organization that defends and fights for caregiver's rights.

ALC (Alternate Level of Care) - Patients are designated "ALC" when they are ready to be discharged from acute care, but the appropriate "discharge destination" is not available - example: suitable long term care bed; specialized housing supports, etc.

Assistive technology devices - Products that improve a person's ability to live and function independently. Low-tech assistive devices include canes and pill organizers, and high-tech items include electric wheelchairs, hearing aids and smartphones.

ALF (Assisted living facility) - Housing for those who may need help living independently but do not need skilled nursing care. The level of assistance varies among residences and may include help with bathing, dressing, meals and housekeeping.

ALS (Assisted living services) – see Assisted living facility.

Attending doctor - An experienced medical doctor who is responsible for the overall care of a patient in a hospital or clinic setting.

Bereavement - The grief of losing a loved one.

Care plan - The role each family member and medical professional will play in the patient's treatment.

Care recipient - The person receiving help from the caregiver to perform daily living activities.

Caregiver burnout - The physical and emotional exhaustion that caregivers experience when the effort put into patient's care is not adjusted for by self-care.

Cardiologist - A medical doctor who specializes in heart disorders.

Case manager - A specialized social worker or healthcare professional who oversees and coordinates the continued care of clinical patients. They provide assessment, planning, facilitation, care coordination, evaluation and advocacy for options and services to meet an individual's and family's comprehensive healthcare needs.

CCAC (Community Care Access Centres) - This is former name for home care coordination agency. New name is HCCSS.

CCP (Coordinated Care Plan) - Multiple team members work together with client and family on a care plan that may involve responsibilities from many different partners in the circle of care.

CHC (Community Health Centres) - A community health center (CHC) is a non-profit clinic that offers affordable, comprehensive primary and preventive care services.

Chronic disease - A condition that lasts one year or more and either requires ongoing medical attention or limits a person's ability to bathe, care for themselves, dress, eat or walk.

Comorbidity - The presence, or coexistence, of more than one disorder in the same person. They can occur at the same time or one after the other. Interactions between the illnesses can worsen the course of both.

Continence - The ability to control bowel and bladder function.

CPR (Cardiopulmonary resuscitation) - Involves giving strong, rapid pushes to the chest to keep blood moving through the body. Usually, it also involves blowing air into the person's mouth to help with breathing and send oxygen to the lungs.

CSS (Community Support Services) - Publicly funded support services under the ministry of health - can include caregivers supports, meals on wheels, seniors active living programs - a wide range of services.

Dermatologist - A medical doctor who specializes in skin disorders.

Discharge planner - A professional who assists patients and their families in developing a plan or method of care for a patient following a hospital or nursing home stay.

ED – Emergency Department (of hospital)

Eligibility - A person is eligible (for a program or service) if they meet the criteria, requirements, terms or conditions set by the program/ service. Review criteria such as written screening procedures and practice guidelines are used by service providers to determine the necessity and appropriateness of health care services.

End-of-life care - A medical plan that includes the patient's and family's wishes for those with a terminal illness.

Endocrinologist - A medical doctor who specializes in hormonal and metabolic disorders, including diabetes.

ER – Emergency Room (of hospital)

Essential Visitor - *(definition used by the Ministry of Health and Ministry of Long Term Care)* defines Essential visitors include a person performing essential support services (e.g., food delivery, inspector, maintenance, or health care services or a person visiting a very ill or palliative resident. A caregiver is a type of essential visitor who is designated by the resident and/or their substitute decision-maker and is visiting to provide direct care to the resident (e.g. supporting feeding, mobility, personal hygiene, cognitive stimulation, communication, meaningful connection, relational continuity and assistance in decision-making).

ETHP – East Toronto's Ontario Health Team

Family or informal caregiver - Any relative, partner, friend or neighbor who has a significant personal relationship with and provides a broad range of assistance for an adult with an acute, chronic, or disabling condition.

Family physician - Health care professional who is trained to provide primary care. This is the doctor that you see first for checkups and health problems; general practitioner who may refer patients to specialist as required.

Friendly Visitor - Friendly Visiting is one-on-one, personal visits by a trained volunteer for seniors who find it difficult to leave their homes, to decrease social isolation.

GE (Gastroenterologist) - A medical doctor who specializes in digestive disorders.

Geriatrician - A medical doctor who has completed a residency in either family medicine or internal medicine and focuses on older adults.

GEM - Geriatric Emergency Management

Health Care Team - Two or more health care professionals working in a coordinated, complementary and agreed-upon manner to provide quality, cost-effective, evidence-based care to a patient and may include the patient, caregiver, a physician, advanced practice nurse,

nurse, physical therapist, occupational therapist, speech therapist, social worker, nutritionist, psychotherapist, counselor or other licensed professionals.

HCC (Home and Community Care) - Home and community services support people of all ages who require care in their home, at school or in the community (e.g. nurse visits, homemaking, personal care etc)

HCCSS (Home and Community Care Support Services) - organizations provide patient care including home care and long-term care home placement services and facilitate access to community services. Home and Community Care Support Services organizations are responsible for deciding who receives care, the level of care you need and for how long. Formerly known as LHINs.

HCP - Health Care Providers

Hospice care - A treatment regime for people who have advanced, life-limiting, often incurable illnesses. Considered a type of palliative care, hospice focuses on the patient's psychological well-being and on managing symptoms of a disease rather than the disease itself, so they can spend their last days with dignity and quality, surrounded by loved ones.

Informed consent - The process of making decisions about medical care or medical experimentation based on open and honest communication among the health care provider, the patient and the patient's family.

IV (Intravenous) – apparatus used to administer fluids through veins.

Interpreter - A person who translates orally from one language into another.

LHIN (Local Health Integrated Network) - This is former name for home care coordination agency. New name is HCCSS.

LTC home (Long Term Care home) - Sometimes called a Nursing Home, a public or private residential facility providing 24/7 supervised care. LTC provides a high level of long-term personal or medical care for chronically ill, disabled and older people who are unable to care for themselves properly.

MHA - Mental Health and Addictions

MoHLTC (Ministry of Health and Long Term Care) - Now separate Ministry of Health and separate Ministry of Long Term Care.

MOW (Meals on Wheels) - A service that delivers daily hot meals to the homes of elderly or disabled people.

Medical Escort - A medical escort is a non-emergency medical service that provides hands-on care to those who are unable to care for themselves or for individuals that require monitoring aboard a commercial airline or private charter. The medical escort can be a doctor, registered nurse, or a paramedic.

Medical History - A narrative or record of past events and circumstances that are or may be relevant to a patient's current state of health. Informally, an account of past specialists' appointments, diagnosis, medications prescribed, diagnostic tests results, hospitalizations, procedures, surgeries and other strictly medical facts.

Nephrologist - A medical doctor who specializes in kidney disorders.

Neurologist - A medical doctor who specializes in nervous system disorders.

NP (Nurse practitioner) - also known as advanced practice registered nurse (APRN). A primary-care provider with graduate training in advanced practice nursing who has the authority to order tests, write referrals and prescribe medicines.

Nursing home - See Long Term Care Home

OT (Occupational Therapist) – A health professional that helps people of all ages who have physical, sensory, or cognitive problems.

OCO – Ontario Caregiver Organization

ODSP – Ontario Disability Support Program

OT (Occupational Therapist) – A health professional that helps people who have physical, sensory, or cognitive problems. OT can help them regain independence in all areas of their lives. Occupational therapists help with barriers that affect a person's emotional, social, and physical needs.

OHIP - Ontario Health Insurance Plan

OHT (Ontario Health Teams) - Ontario Health Teams are a new way of organizing and delivering care that is more connected to patients in their local communities. Under Ontario Health Teams, health care providers (including hospitals, doctors and home and community care providers) work as one coordinated team - no matter where they provide care.

OW (Works) - Provides money for food, shelter and other costs to people in financial need who meet the eligibility criteria.

Ophthalmology - A medical doctor who specializes in eye disorders and surgery.

Orthopedic surgeon or orthopedist - A medical doctor who specializes in bone and connective tissue disorders.

Osteopath - also called a doctor of osteopathic medicine. A doctor who has completed four years of medical school and has had 300 to 500 additional hours in the study of hands-on manual medicine and the body's musculoskeletal system. These doctors are state licensed and may have completed a two- to six-year residency and passed state examinations to become board certified.

Otolaryngologist or otorhinolaryngologist - A medical doctor who specializes in ear, nose and throat (ENT) problems.

Outpatient care - also called ambulatory care. Health care procedures and treatment that do not require overnight hospitalization.

Palliative care - Specialized medical care that focuses on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family. Unlike hospice care, which is typically given to people with terminal conditions who are nearing the end of life, palliative care can coincide with treatments to arrest or cure a disease.

Patient advocate - A professional who can resolve concerns about someone's health care experience, particularly problems that cannot be taken care of immediately.

POA (Power of Attorney) - is the legal document that gives someone else the right to make decisions on your behalf.

PSW (Personal Support Worker) - Trained and certified health care worker who assists a patient in the home. Duties typically include help with personal hygiene and other self-care, such as bathing, dressing, eating, going to the bathroom, maintaining personal appearance and walking, meal preparation, grocery shopping, exercise, light household work and monitoring the patient's condition.

Podiatrist - A doctor with specialized training in treating foot and ankle problems.

Primary care - Direct provision of first-contact services (by providers such as family physicians, nurse practitioners, pharmacists, and telephone advice lines). Primary care focusses on health promotion, illness and injury prevention, and the diagnosis and treatment of illness and injury.

Psychiatrist - A medical doctor who specializes in emotional and mental disorders.

Psychologist - A specialist, but not a medical doctor, who can talk with patients and their families about emotional and personal matters and can help them make decisions.

Quick Response Team - Provides crisis intervention at home to eligible clients when required aimed at preventing avoidable hospital admission, provide crisis intervention at home and to facilitate early hospital discharge. The QRT team includes physiotherapists, occupational therapists, social workers, nurses and home support workers.

Radiologist - A medical doctor who specializes in X-rays and related procedures such as computed tomography (CT) scans, magnetic resonance imaging (MRI) and ultrasound tests.

RN (Registered nurse) - A health professional who has graduated from a nursing program, passed a state board examination and has a state license.

RPN (Registered Practicing Nurse) – (see above) RNs and RPNs study from the same body of nursing knowledge, RNs study for a longer period of time, allowing for a greater depth and breadth of foundational knowledge.

Reactivation Care Centres - The Reactivation Care Centres are designed to help patients who no longer need acute care services, but often find themselves waiting for an alternate care facility, such as convalescent and long-term care.

Rehabilitation hospital - A medical facility providing therapy and training for the restoration of physical function or cognitive skills following a serious injury, illness or medical event (such as a stroke).

Reintegration Care Units - The Reintegration Care Units (RCUs) provides patients with a short-term safe, community based and supportive place to go post-hospital discharge.

RPM (Remote patient monitoring) - A subcategory of telehealth services that allows patients to use mobile medical devices and technology to gather patient-generated health data, such as weight, blood pressure and heart rate, and send it to health care professionals.

Respite care - Short-term or temporary care of a sick, disabled or older person for a few hours, days or weeks, designed to provide relief to the regular caregiver.

Retirement home - A residence that accommodates older adults who require little to no help with everyday tasks and have few medical needs.

RGI (Rent Geared to Income) - RGI is subsidized housing. The rent is based directly on the tenant's income, usually 30 per cent of the gross monthly household income.

Rheumatologist - A medical doctor who specializes in pain and other symptoms related to joints and other parts of the musculoskeletal system, such as bones, cartilage, ligaments, muscles and tendons.

SALC (Seniors Active Living Centres) - offer social, cultural, learning and recreational programs for seniors. By promoting wellness, social connections and education, these programs can help reduce social isolation and help seniors stay active, independent and engaged.

Self-care - The importance of regular exercise, healthy food, and regular doctor visits. Self-care also includes allowing for a respite, a regular sleep schedule, and seeking professional help when needed.

SLP (Speech Language Pathologist) - Also called a speech therapist, is a health professional who specializes in the diagnosis, treatment, and prevention of communication and swallowing problems

SPO - Service Provider Organization

SDM (Substitute decision maker) - The person or people who are legally allowed to make healthcare decisions for you if you are not capable of making the decision yourself.

Support group - An online, in-person group of people that understand the challenges of caregiving and are able to offer advice from their own experience.

Support network - The people in a caregiver's life that provide respite care, emergency care, and/or emotional support including family, friends, medical professionals, and fellow caregivers.

TCHC – Toronto Community Housing Corporation

TSHC - Toronto Seniors Housing Corporation

Transitional Care Unit - A transitional care unit is, most often, a short-term care facility (less than 21 days) for medically complex patients transitioning from the hospital to home, or from one care setting and to another. Transitional care is intended to provide the right level of care for patients to support their move back to the community or to another level of care (e.g. high intensity rehabilitation).

TTC - Toronto Transit Commission

Urologist - A medical doctor who specializes in disorders of the male reproductive system as well as the male and female urinary tract.

Vital signs - Signs of life — specifically, a person's heart rate (pulse), breathing rate, body temperature and blood pressure. They show doctors how well a person's body is functioning.

Visitor Policy - A document that defines the healthcare facility's general standards of behavior and provides guidance for visitors.